

Summary of the Institute of Medicine's Reports on Cancer Survivorship

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The Children's Cause for Cancer Advocacy

Institute of Medicine

National Academies of Science

- ❖ To serve as adviser to the nation to improve health
- ❖ To provide unbiased, evidence-based, and authoritative information and advice on health and science policy to policy-makers, professionals, leaders in every sector of society, and the public at large

National Cancer Policy Board

- ❖ Committee of the IOM
- ❖ Established 1997 to address broad policy issues that affect cancer in the U.S.
- ❖ To recommend ways to advance the Nation's effort against cancer
- ❖ 20 members outside federal government:
health care consumers, providers, and
researchers in various disciplines in the
sciences and humanities

Improving Quality Cancer Care

- ❖ *Ensuring Quality Care* (1999)
- ❖ *Improving Palliative Care for Cancer* (2001)
- ❖ *Meeting the Psychosocial Needs of Women with Breast Cancer* (2004)
- ❖ Report on quality care in adult survivorship (forthcoming 2005)

Childhood Cancer Survivorship: Improving Care and Quality of Life

*Maria Hewitt, Susan L. Weiner and
Joseph V. Simone, Editors*

Groundbreaking Report

- ❖ Comprehensive review, including expert input
- ❖ Careful peer review
- ❖ Analysis of policy implications of the hundreds of thousands of children now surviving cancer

General Features

- ❖ “Childhood” cancer is defined as cancer in one under 20 years of age
- ❖ NCI definition used:
from diagnosis to death
- ❖ Method: analysis of evidence + NCPB recommendations

The Price of Success

- ❖ At least $\frac{2}{3}$ of survivors have at least one late effect
- ❖ About $\frac{1}{4}$ of these survivors have serious or life threatening late effects

Types of Late Effects

- ❖ Second malignancies
- ❖ Neuropsychological (learning disabilities)
- ❖ Cardiopulmonary
- ❖ Endocrine (growth and fertility)
- ❖ Psychosocial
- ❖ Musculoskeletal
- ❖ *Variable in nature, time of onset and exposure*

Why and When

- ❖ Cytotoxic agents, surgery and radiation given during periods of physical, neurological, psychological and social growth and development
- ❖ May emerge soon after therapy is completed or years to decades later
- ❖ Prematurely experience diseases of aging

Late Effects: Studies on Prevention and Management

- ❖ Some are preventable by dose reduction, elimination or substitution of a less toxic agent
- ❖ The impact of some may be mitigated by early intervention
- ❖ Close follow-up is the key to both

Recommendations

I. Guidelines for care

Recommendations

- I. Guidelines for care
- II. Standards for systems of follow-up care

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- III. Awareness of late effects

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- V. Role of public service programs
- VI. Access to health care services
- VII. Research needs

I. Follow-up Care Guidelines

EVIDENCE

- ❖ When report published, there were no guidelines for follow-up care

RECOMMENDATION

- ❖ Guidelines development is a first priority

II. Systems of Follow-up Care

EVIDENCE

- ❖ No widely accepted systems
- ❖ Patients often lost to follow-up, have inadequate and unsystematic follow-up
- ❖ Most provider institutions have no systematic follow-up appropriate to age of patient and nature of late effects

II. Follow-up Care Systems

Recommendations

- ❖ Define a minimum set of standards for follow-up care linking primary and specialty caregivers long-term
- ❖ Ensure such systems are in place in treating institutions
- ❖ Evaluate alternative models of care delivery

III. Survivors' Awareness of Late Effects

Evidence

- ❖ Majority of cancer survivors are unaware of their risk for late effects and the need for follow-up care

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Recommendations

- ❖ Improve awareness of late effects and their implications to long-term health among childhood cancer survivors and their families

IV. Professional Training

EVIDENCE

- ❖ Too few advanced practice nurses to staff follow-up clinics (usually responsible)
- ❖ Oncologists and primary care docs often lack knowledge of late effects
- ❖ cursory coverage of issues in medical texts
- ❖ 1 in 300 ambulatory care visits by children is cancer related; increase is inevitable

IV. Professional Training

Recommendation

- ❖ Improve professional education and training about late effects of childhood cancer and their management for both specialty and primary care providers

V. Service Programs - Public

EVIDENCE

- ❖ Many problems of cancer survivors are shared by children and adults with other chronic/disabling diseases/conditions
- ❖ Coordination among programs in DHHS, DOE and at state is poor
 - ◆ Eligibility, covered services differ
- ❖ No program has the specific mission to address needs of childhood cancer survivors

V. Public Programs

Recommendation

- ❖ Health Resources and Services Administration & Child Health Bureau + partners should be supported to implement Health People 2010 goals for Children with Special Care Needs, including a national communication strategy, capacity building, setting standards, and establishing accountability
- ❖ Dept. of Ed. has important service role

VI. Access to Health Care Services

Evidence

- ❖ Insurance often does not cover cancer survivors and their special health and service needs

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Evidence

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Recommendation

- ❖ Federal, state & private efforts needed to optimize survivors' access to resources and delivery systems through health insurance reforms and public safety net programs

VII. Research Needed

EVIDENCE

- ❖ Continued, systematic follow-up of cohorts of survivors can reveal the extent of late effects and suggest prevention and amelioration strategies
 - CCSS & some cancer centers yielding vital data
- ❖ Treatment modifications can reduce late effects
- ❖ Little work done on interventions

VII. Research

RECOMMENDATIONS

- ❖ **Funding organizations should increase support to develop strategies to prevent or ameliorate late effects**
- ❖ **Studies needed on prevalence and etiology, treatment modifications, interventions, and improvements in overall quality of care**

SO - WHO IS
RESPONSIBLE?

I. Guidelines for follow-up care

RECOMMENDATION

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www.childrensoncologygroup.org

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WHO?

- COG Late Effects Committee developed the guidelines!

www.childrensoncologygroup.org

II. Standards for systems of follow-up care

RECOMMENDATION

- ❖ Define minimum standards to link primary and specialty caregivers
- ❖ Ensure such systems in place in treating institutions
- ❖ Evaluate alternative models of care delivery

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WHO?

- NCI should convene experts
- Professional societies should endorse
- COG institutions should ensure services available at institutions
- State cancer control plans for services
- Demonstration & eval. of programs through HRSA

III. Awareness of late effects

RECOMMENDATION

- ❖ Improve survivors' and families awareness of late effects and long term health implications

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WHO?

- Clinicians: begin at diagnosis
- NCI and nonprofit health educator and advocacy groups

IV. Professional education

Recommendation

- ❖ Improve education and training about late effects and management for specialty and primary care providers

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WHO?

- Professional societies
- Primary care programs
- Onc training programs
- Onc board exams
- NCI website
- Interdisciplinary mtgs

V. Strengthen public service programs

RECOMMENDATION

- ❖ HRSA & Matl/Child Health Bureau & other DHHS prgms should be supported to implement Health People 2010 goals for Children with Special Care Needs: a national communication strategy, capacity building, setting standards, and establishing accountability

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WHO?

- DHSS, HRSA
- CMS, Medicaid
- S-CHIP Programs
- Dept.Ed Early Intervention
- Dept.Ed Special Ed

VI. Access to health care services

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WHO?

- Federal & state legislation on specific issues
- Private & public insurers to provide appropriate services and range of providers

VII. Research

RECOMMENDATION

- ❖ **Increase support to prevent or ameliorate late effects**
- ❖ **Research prevalence, etiology, treatment modifications, interventions, and improvements in overall quality of care**

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WHO?

- NCI
 - CCSS
 - Health outcomes
- COG f-up for clin trs
- Other NIH institutes
- Private funders, e.g., ACS

Summary

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- ⌚ NCI needs to take coordinating role
- ⌚ Late effects are a moving target
- ⌚ Longitudinal research and follow-up are vital to preserve our investment
- ⌚ Information dissemination to professionals, survivors and families is essential to improving and preserving our children's lives



SOCIETAL AND PROFESSIONAL COMMUNITY RESPONSIBILITY

Report available at

Institute of Medicine Website

<http://www.iom.edu>